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ABSTRACT

This report summarizes the employment experiences of 103 individuals with HIV/AIDS in the context of the existing service delivery system. Seventy-four individuals with HIV/AIDS completed surveys about their employment-related experiences. In addition, five focus groups were conducted throughout Massachusetts with 29 individuals with HIV/AIDS. Sixty-eight percent of study participants were unemployed. Individuals with HIV/AIDS described employment as a central source of well-being and dignity. Among work-related obstacles and concerns were a fear of losing Social Security benefits (if working) and a fear of discrimination. Unemployed individuals wanted to return to work but felt that existing AIDS or state agencies were not meeting their job training and placement needs. Employed individuals were concerned that requested job accommodations (such as schedule modifications) were often not granted. Respondents reported using personal supports such as friends or family before professional resources. Specific recommendations and suggested resources are offered to individuals with HIV/AIDS concerning Social Security benefits, employment rights, health insurance, and vocational rehabilitation services. (DB)

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Research ⇒ Practice

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Employment Needs of Individuals with HIV/AIDS

Jaimie Cirilla Timmons and Sheila Lynch Fesko

ED 410 699

Introduction

Employment concerns are becoming increasingly important to individuals with HIV/AIDS. Employment situations and relationships can be affected as individuals with HIV/AIDS struggle with disclosure of their diagnosis and strive to balance work demands with their medical needs. Although a wide range of resources are available for individuals with HIV/AIDS, services specifically targeted at employment are limited.

As a result, The Institute for Community Inclusion at Children's Hospital began the Employment Project for People with HIV/AIDS. This project has three primary goals:

- to better understand the employment needs of individuals with HIV/AIDS
- to provide support to individuals with HIV/AIDS to assist them in maintaining and/or obtaining employment.
- to build the capacity of existing organizations that provide services to individuals with HIV/AIDS to provide employment-related support.

As part of this project, the Institute for Community Inclusion has collected information from both individuals with HIV/AIDS and employment service providers. This report summarizes the employment experiences of individuals with HIV/AIDS in the context of the existing service delivery system.

Participants

A total of 103 individuals with HIV/AIDS participated in the study. Seventy-four individuals with HIV/AIDS completed surveys that focused on employment-related experiences. In addition, five focus groups were conducted throughout Massachusetts with 29 individuals who have HIV/AIDS. Study participants were primarily male (72%) and Caucasian (57%); 21% were Hispanic and 16% were African-American. Seventy-nine percent were between the ages of 31-50.

Sixty-eight percent of the study participants were unemployed. Eighty-four percent of these unemployed individuals reported leaving their jobs voluntarily; however, their decisions were based primarily on concerns directly related to their diagnosis. Employed study participants held a variety of jobs, with a significant percentage (24%) employed in the human services field.

Findings

Individuals with HIV/AIDS described employment as a central source of well-being and dignity.

Individuals concluded that their health status not only effects the likelihood of work, but the quality and choice of employment options.

> *"You keep your mind distracted with work. It helps us rehabilitate ourselves in a positive way. All of this contributes to the quality of life. It is always better to work. It is something that motivates you, that fulfills you, that actually (gives) something in return."*

Work-related Obstacles and Concerns

Social Security Benefits

Employed individuals were concerned that their income would make them ineligible for cash and medical benefits. In addition, they were fearful that if the need to stop working were to arise, they would face a lengthy re-application process and be without health insurance.

Unemployed focus group participants concluded that the risk of losing Social Security benefits can often outweigh the advantages of returning to work.

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Fear of Discrimination

Survey respondents and focus group participants were concerned about the psychological stress caused by the fear of discrimination in the workplace.

Although a rather small percentage (11%) of survey respondents indicated they had actually experienced discrimination, many felt the anxiety caused by the possibility of discrimination was detrimental to their health.

Specific Needs of Unemployed Individuals with HIV/AIDS

Unemployed individuals:

- Indicated a desire to return to work and therefore were most concerned with job search and job placement assistance.
- Felt that AIDS Service Organizations could not provide adequate assistance with job training and job searches.
- Reported that the state vocational rehabilitation agency was helpful with job training assistance, but significantly less responsive to their job placement needs.

Specific Needs of Employed Individuals with HIV/AIDS

Employed individuals:

- Were most concerned with assistance related to job accommodation.
- Indicated that 63% of all the accommodations requested were not granted. Examples of accommodations requested included variations in job duties and schedule modifications.

Supports Utilized to Address Work-Related Issues

Survey respondents reported the use of personal supports such as friends or family before professional resources such as therapists or case managers.

Unemployed survey respondents were more likely to turn to professional resources than employed survey respondents.

Only 23% of the survey respondents reported using their state vocational rehabilitation agency in dealing with employment-related issues.

When state vocational rehabilitation services were utilized, focus group participants reported feeling discouraged by long waiting lists that they encountered.

Focus group participants also reported that AIDS Service Organizations were only partially responsive to their employment concerns, and they generally did not turn to this resource when addressing work related challenges.

"I'm affiliated with a lot of different agencies...like five. Each agency gives me something different. Of all the agencies that I'm affiliated with, (not one) covers everything that I need as being HIV (+)"

Implications and Recommendations

The information provided by study participants suggests that employment needs are becoming an increasingly important concern often insufficiently addressed by the current service system. The results of this project suggest the need to develop strategies for individuals striving to overcome employment difficulties. The following recommendations are designed to provide individuals with HIV/AIDS additional resources and information to assist in addressing their employment-related concerns.

Social Security Benefits

- ❒ Understand, or identify someone who understands, work incentive programs for individuals who receive either Supplemental Security Income or Social Security Disability Income. Incentive programs often allow individuals to continue to work while maintaining health insurance benefits and eligibility for cash benefits.

- ❒ For additional information on work incentive programs call the Social Security Administration at 1(800)772-1213 to order the *Red Book on Work Incentives for People with Disabilities* (8/95: Pub No. 64-030).

- ❒ Another useful resource published by the Social Security Administration is *A Guide to Social Security and SSI Disability Benefits for People with HIV* (6/95; Pub No 05-10020). This booklet may be helpful in understanding the kinds of disability benefits you might be eligible for from the Social Security or Supplemental Security Income Programs. Call the Social Security Administration at 1(800) 772-1213 to order.

- Identify and maintain communication with one worker at Social Security. Document every interaction, as keeping organized will help the service provider assist you more efficiently. Since Social Security is such a large system, maintaining organized records and consistent contact with one person will enable your worker to deliver the most thorough services possible.

Employment Rights

- Educate yourself about your employment rights under The Americans with Disabilities Act of 1990 (ADA). This law entitles individuals with HIV/AIDS to reasonable accommodation on the job and ensures against discrimination on the basis of one's health status.

- A valuable resource for technical assistance on the provisions of the ADA is the Mid-Atlantic ADA Information Center at 800-949-4232. The organization also distributes federally-approved ADA regulations and materials.

- For additional information on the ADA, the School of Industrial and Labor Relations at Cornell University has published a fact sheet on The Americans with Disabilities Act and the rights of individuals with HIV/AIDS. Contact the ILR Program on Employment and Disability, Cornell University, 102 ILR Extension, Ithaca, New York 14853-3901; or call (607) 255-2906.

- Advocate for job accommodation by clearly identifying your needs and identifying potential solutions. By understanding your company's policies and formulating potential solutions in advance, you can make it easier for your supervisor to incorporate job accommodations into the process.

- Understand in advance that requesting reasonable accommodation might require some negotiation. This is not meant to discourage requests for accommodation, but rather to clarify that situations requiring patience and negotiation may arise.

- Consider utilizing the Job Accommodation Network by calling 800-JAN-7254 or 800-ADA-WORK (voice/TDD), a national resource specifically designed to assist individuals and businesses with job accommodation needs.

- For additional information on issues related to HIV/AIDS in the workplace, the CDC Business Responds to AIDS and Labor Responds to AIDS Program (BRTA/LRTA) has established a new World Wide Web site located at http://www.brta-lrta.org. The web site offers information on BRTA/LRTA and presents statements from business, labor, and community leaders about successful programs. For more information or referrals, call the CDC Business and Labor Resource Service at (800) 458-5231.

- Do not allow your HIV status to influence the job search. Employers may not ask job applicants about the existence, nature or severity of a disability. They may ask, however, about your ability to perform specific job functions.

- In most instances, requests for job accommodation should be able to be resolved at the workplace. However, if negotiation efforts are unsuccessful and you feel you have been discriminated against, consider contacting the ADA Mediation Project in Boston, Massachusetts. Professionally trained, neutral mediators are available to assist disputing parties in creative, cost effective and mutually acceptable resolutions. Call (617) 451-2093 or 800-439-2370 TTY/TDD.

- If mediation efforts are unsuccessful, legal resources do exist. Both the Justice Resource Institute (617-450-0500) and GLAD (617-426-1350) in Boston, Massachusetts, specialize in the provision of legal advocacy to individuals with HIV/AIDS.

- Another useful resource is entitled *HIV and Discrimination: A Handbook for Resolving Problems*. In Massachusetts call the Boston City Commission for Persons with Disabilities at (617) 635-3682 for a copy of this handbook.

- Investigate your rights under The Family and Medical Leave Act of 1993 (FMLA). The FMLA requires an employer to grant up to 12 weeks of unpaid, job-protected leave to employees having a serious health condition that makes them unable to perform their job.

- For more information about FMLA, please contact the nearest Wage and Hour Division, listed in the phone book under the U.S. Government, Department of Labor, Employment Standards Administration.

Health Insurance

- If health insurance is not available through work, seek alternative strategies to meet your health insurance needs. For example, CommonHealth in

Massachusetts provides full or supplemental health care benefits to working adults with disabilities. Members pay a monthly premium according to a sliding fee based on their income and family size. In Massachusetts, call the Division of Medical Assistance Enrollment Center at 1-800-242-1340 or (508) 828-4600 for more information.

- The Family and Medical Leave Act of 1993 not only requires an employer to grant job-protected leave, but the employer must maintain the employee's medical insurance coverage. *A Q & A Guide To FMLA*, published by the Women's Legal Defense Fund, may be helpful (1875 Conn. Ave., NW Suite 710, Washington, D.C., 20009; $3.50)

- The Health Insurance Portability and Accountability Act protects individuals who would be denied insurance coverage on the basis of a pre-existing condition. It allows individuals to change jobs without worrying about being denied by a new insurance company. For more information in Massachusetts, call the Insurance Division of the Inspector General's Office at (617) 521-7794.

Vocational Rehabilitation Services

- State vocational rehabilitation (VR) agencies provide employment support services to individuals with disabilities. Most offices have a counselor specifically identified as a conduit to work with people who have HIV/AIDS. In Massachusetts, call the Massachusetts Rehabilitation Commission at 1-800-245-6543 to find out more about VR services that are available.

- After applying for VR services, an assigned counselor will work with you to resolve your employment-related questions and assist in defining your needs in your first few meetings.

- Try to be as clear as possible about what you wish to accomplish through the use of vocational rehabilitation services and consider options for achieving your goals. Maintaining clarity around your needs will ultimately allow your counselor to assist you in fulfilling your employment-related goals.

- Vocational rehabilitation services are designed to ensure that the rights of individuals are protected. However, if a situation arises that you are not able to resolve with your counselor, both a formal appeals process and Client Assistance Programs exist to protect the rights of individuals in the VR process.

National Resources

- National AIDS Hotline 800-342-AIDS. For Spanish access, 800-344-SIDA; or for deaf access, 800-AIDS-TTY

- ADA Regional Disability and Business Technical Assistance Center Hotline 800-949-4232 (voice/TYY)

- The Equal Employment Opportunity Commission 800-669-4000; 800-800-3302 (TTY); or 800-669-EEOC (publications)

- National Leadership Coalition on AIDS, 1730 M Street, NW, Suite 905, Washington, DC 20036, 202-429-0930

- CDC National AIDS Clearinghouse, Business and Labor Resource Service, 800-458-5241.

Vocational prospects can be challenging yet individuals with HIV/AIDS report that the benefits of working outweighed the difficulties. What remains promising is an increasing number of resources which are becoming available to assist individuals with HIV/AIDS in addressing employment-related concerns. With improved access to resources and supports, individuals with HIV/AIDS can continue to pursue and achieve their employment goals.

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